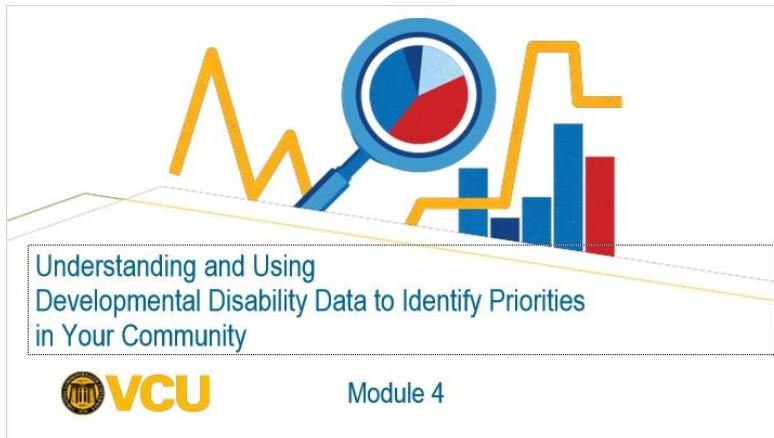# Module 4 – Using Data for Planning

1.1 Using Data for Planning

Notes:

Welcome to the "Understanding and Using Developmental Disability Data to Identify Priorities in Your Community" module. It is likely that you will be asked to examine available data, statistics and analyses to make decisions about how to best support people with disabilities. In this module we will examine some myths about using data and ask some questions of the data to make them useful.

1.2 Partnership for People with Disabilities

Notes:

This module is part of a series of training developed by Project Living Well staff who work at the Partnership for People with Disabilities at Virginia Commonwealth University. The Partnership serves as Virginia's University Center for Excellence in Developmental Disabilities. Project Living Well is a grant from the U.S. Department of Health & Human Services' Administration on Community Living. More information about this project and the Partnership can be found by calling (804) 828-3876 or visiting www.partnership.vcu.edu

1.3 Data

Data and Statistics

	A	B	C	D	E	F	G	H
1	function	gene	spo-early	spo-mid	heat 0	heat 10	heat 20	
2	Proteas	YDR427W	0.301	0.546		-0.009	0.024	
3	Proteas	YGL048C	0.208		-0.061	-0.039	0.003	
4	Resp	YBR039W	-0.179	-0.219	-0.097		-0.011	
5	Ribo	YKL180W	-0.085	-0.161	-0.061	-0.265	-0.419	
6	Ribo	YHR021C	-0.216	-0.253	-0.228	-0.168	-0.228	
7	Resp	YDR178W	0.017	0.07	0.058	0.286	0.205	
8	Resp	YLL041C	0.115		0.033	0.262	0.054	
9	Resp	YOR065W	0.005	-0.023	-0.038	0.222	0.088	
10								

VCU

Notes:

Let's start with a basic definition of data. Data are facts or perceived facts about the world, often converted into numbers, words, and other forms that make them easier to analyze and interpret. Often these data are stored in formats such as the one in the picture. Statistics, often answering how much or how many, come from analyzing and interpreting data. In this module, we are concerned with using data and statistics for decision making.

1.4 Are People in my Community Socially Included?

Are People in my Community Socially Included?

Virginia's 2018 National Core Indicator Data (807 respondents with IDD)

❓ Do the statistics provided sufficiently describe whether or not people are socially included?

❓ Can you use the available information to make plans that could improve opportunities for social inclusion?

VCU

Notes:

Let's begin by looking at two data sources about people with intellectual and developmental disabilities (which we will refer to as, people with IDD) and social inclusion. As we do, I want you to be asking yourself two questions. First, do the statistics provided sufficiently describe whether or not people are socially included? And second, can you use the available information to make plans that could improve opportunities for social inclusion?

How do we know when people with IDD are socially included? Researchers say that when people participate in community activities with others whose company they enjoy, then they are socially included.

In 2018, 807 adults with IDD living in Virginia who had Medicaid Home and Community Based Services participated in in-person National Core Indicators interviews. The interview responses were converted into data producing the following statistics:

88% said they could go out when they wanted to.

11% had jobs in the community, and 49% volunteered in the community.

93% of respondents went shopping in the community and almost half of them went 5 or more times in the month prior to responding.

10% went shopping with friends.
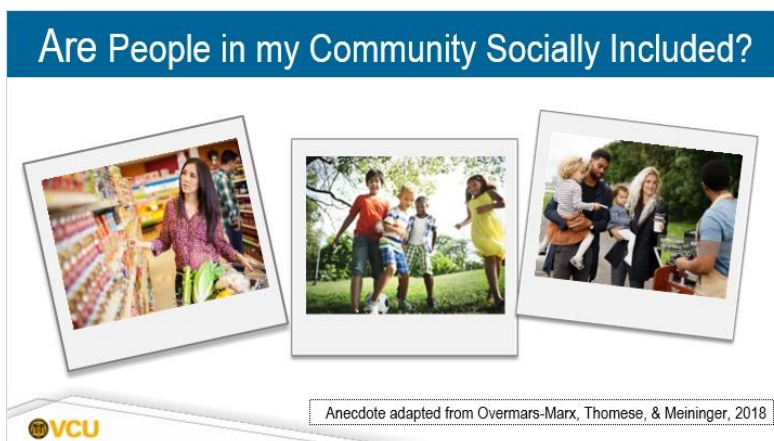
So are people with IDD in Virginia socially included?

Responses (Slide Layer)

Question (Slide Layer)

1.5 Are People in my Community Socially Included?

Notes:

One community sought the opinions from an infrequently used resource: people with IDD. These people who received Home and Community Based Services and lived either independently or in group homes, took pictures of various parts of their community and then told stories about how the pictures were related to social inclusion. Pictures and stories were considered data, and therefore, knowledge was built by people with IDD.
Data showed that the following factors were associated with increased social inclusion:
When shopping at local shops and eating at restaurants, where people were recognized, known, and acknowledged by staff and customers.
When people were working and volunteering in their community they had more opportunities to interact and build relationships.
Participating in community activities (getting coffee, going to the gym, going to church) gave people chances to meet others.
Having access to walkable neighborhoods with green spaces, such as parks, allowed for meaningful encounters with others utilizing public spaces.
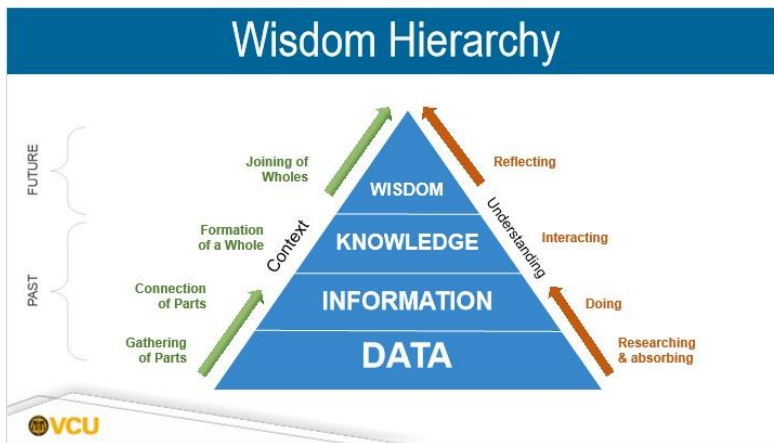Were they socially included in their Virginia town?

shopping (Slide Layer)

working and volunteering (Slide Layer)

participating in community (Slide Layer)

Question (Slide Layer)

1.6 DIKW model/pyramid

Notes:

These two examples may not provide a definitive answer to the question: "Are people with IDD socially included?" However, they do provide different pieces to a larger puzzle. They allow us to make connections between those pieces and they also allow us to know what worked for some people in some places. And, we have some context for the data.

If we look at the Wisdom Hierarchy model, we have moved from data-- just numbers or pictures-- and we have added context about the who, what, when, and where, that elevates our data to information. The data on social inclusion came from different methods and contexts. They provided different perspectives. But when we combine the information we can start looking forward, using what we know to make recommendations for improving social inclusion in different communities.

We know that being able to go out is good, but being able to see or be with friends in community contexts can be improved. We also know that employment and volunteerism was important for social inclusion but community employment was low overall. Take a moment to think about what recommendations you might make given what we know now.

Moving forward, data may look very different based on perspective, method, and context.

Giving data a context and combining multiple perspectives will prepare us to use information for action and to strengthen the decisions we make.

1.7 Myth or Fact: Data Edition

Notes:

Before asking more questions of data let's consider some commonly held ideas about using data and determine whether those ideas are myths or facts.

### 1.8 Only scientists and academics use data to make decisions

Notes:

Is this statement a myth or a fact?...."Only scientists and academics use data to make decisions."
If you said, "Myth", you're right! In general, people commonly use data to make decisions. Such processes are the foundation of learning. A child drawn to a lamp out of curiosity may touch a hot lightbulb. The child will use that information

to decide not to touch lit lightbulbs in the future. We know when certain bills can be paid, because we know when our paychecks are issued. We use data every day to help with learning and decision making.

1.9 Advanced statistics knowledge is required.
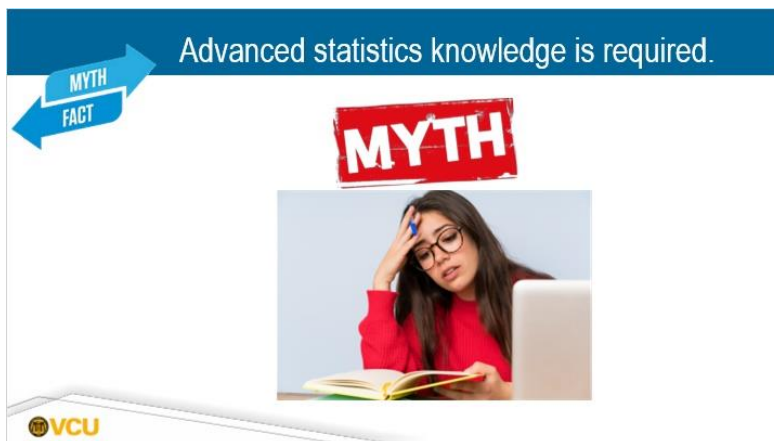
Notes:

 Myth or fact? You need training or advanced training in statistics or data analysis to make data driven decisions.
You're right! It's a Myth. You do not need to be an analyst to use data- this is similar to the first myth. Your goal is not to create complex statistical models but rather to use the resources available to you to understand the contexts of data, to ask good questions, and talk to others about what you believe data to mean and compare to others' interpretations.

1.10 Everyday Data Use

Notes:

Beyond our own experiences we interact with data and information collected from other sources to help us make decisions. Shopping online we may see a review with a one star rating, saying the product is "disappointing". We may also read a review with a 5 star rating saying a product is "brilliant." We'll also consider the amount of reviewers providing 4 or 5 star reviews and compare them to the amount of 1 and 2 star reviews to help us decide whether or not to buy the product (96% vs 2% in this case). Similarly, we may consider the odds of rain provided by a weather person to decide whether to carry an umbrella.

1.11 Lived experiences provide useful data

Notes:

Myth or fact? Lived experiences provide useful data.
Fact! Personal stories are valuable. They inform the contexts in which other data function- the relationships, barriers, power dynamics and histories. Your perspective contributes to a more cohesive group voice. As the data pyramid suggests, your lived experiences provide an account from a specific position that informs the ways that you interpret data. Multiple accounts can take information and transform it into useful, contextualized knowledge.

Pyramid (Slide Layer)
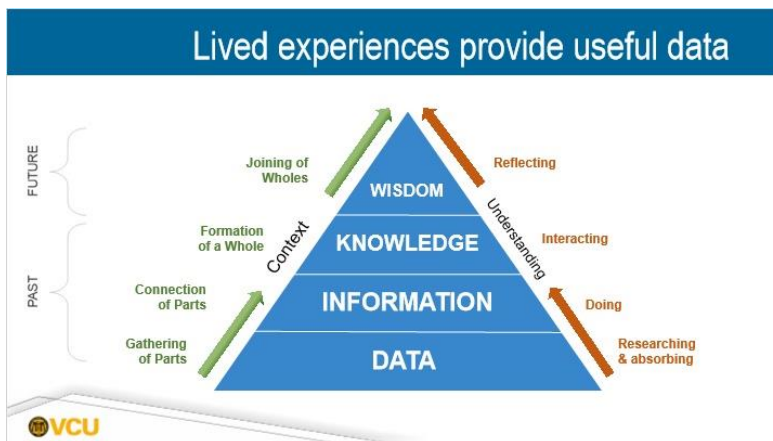
1.12 Knowledge Production

Notes:

Keeping an open mind and including multiple voices and perspectives will strengthen your ability to make good decisions with data. Please keep this in mind when people with disabilities and their families provide personal insights

---

and experiences. These perspectives are essential and can be folded into a larger conversation with multiple data sources.

## 1.13 One dataset can tell you everything you need to know about a sample of people.

Notes:

Myth or fact? One dataset can tell you everything you need to know about a sample of people.
You're right. This is a myth. What is certain is that any one dataset will never tell you everything you need to know about any group of people. Depending on the questions you ask of data, even multiple datasets will likely not tell you everything you need to know about a situation or group, such as employment for Virginian's with IDD.

1.14 Which Employment Rate is TRUE?
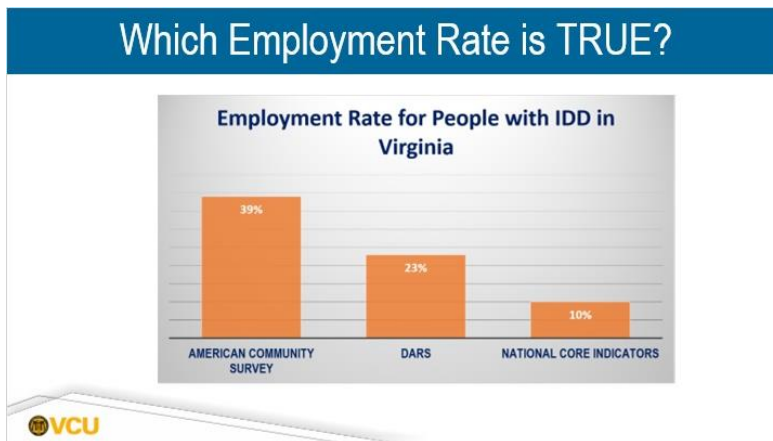
Notes:

Let's consider what 3 datasets tell us about employment for people with IDD in Virginia. Which one of these employment rates accurately represents people with IDD?
We probably need more information.

1.15 Data: Questions and Context

Notes:

Where data come from, how they are collected and who the data represent are valuable considerations when using data for decision making. The American Community Survey says 39% of people with disabilities in Virginia were employed in 2018. These data include information about people with IDD but are

not independent of other people with other disabilities. These data are not false but the data from the American Community Survey reporting on Virginian's with disabilities of all types may be of less use for us than information directly related to our population of interest: working-aged adults with IDD -- as reported in the data from the Department of Aging and Rehabilitative Services and the National Core Indicator's In person Survey.

Take a moment to consider some other questions you may want answered when considering the remaining datasets.

1.16 Asking questions of data
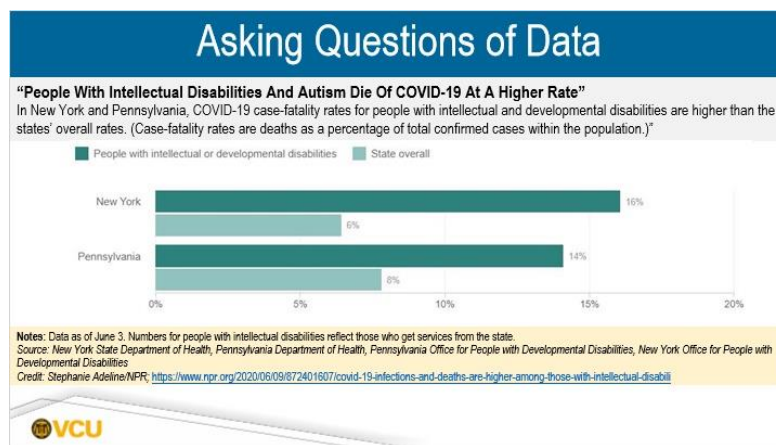
Notes:

This graphical representation of data was included in a recent National Public Radio story. Take a moment to carefully study the information on this slide. Please pause your video and develop some questions you might want to ask of the data.

1.17 Introduction

Notes:

Data from the previous slide have been called into question by advocacy groups because they appear to suggest that having a disability is the reason for greater mortality rates for those who get COVID-19. The mortality could be because people with IDD have more underlying or co-occurring conditions, or could be because they are more likely to live with non-family members, or could be because their access to health care is not as robust as people without disabilities. Asking additional questions of data can help you gain information to help you make your decisions. Here are some examples:

- Who did or did not have the opportunity to contribute to the data? (How were the data collected? Who was included or excluded?)

- Who collected the data?

- When were the data collected?

- What tools were used to collect the data? Were the tools accessible?

- For what purposes were data collected?

- How do findings compare with findings for similar groups in different places or other years?

- Are there other data available for comparison on the same topic?

- Is there persuasion accompanying the chart and is that persuasion accurate?

Questions (Slide Layer)

1.18 Module Development Source

Notes:

The module developers graciously acknowledge the following source materials used for this presentation.

1.19 Additional Resources for Learning

Additional Resources for Learning

Data

What is data:
https://www.lib.umn.edu/datamanagement/whatdata

Types of data in statistics:
https://towardsdatascience.com/data-types-in-statistics-347e152e8bee

Data, information, knowledge, Wisdom:
https://www.systems-thinking.org/dikw/dikw.htm

VCU

Notes:

Thank you for thinking critically about the data that were provided throughout this module. You are invited to continue using multiple data sources and asking questions of data that you receive so that data can be used to make recommendations.
These next two slides include supplementary resources and information that can be used to help unpack data. These resources include useful terms and practice activities for making conclusions and recommendations from available data. Resources for additional learning can be reviewed by clicking on the links provided here and on the next slide.

1.20 Supplementary Resources

Supplementary Resources

Data and Disability
- DBHDS employment reports
  - https://dbhds.virginia.gov/developmental-services/employment
- National Core Indicators.
  - National: https://www.nationalcoreindicators.org/
  - Virginia: https://web.partnership.vcu.edu/nci/
- New Hampshire disability research RRTC
  https://researchondisability.org/
- Cornell University Disability statistics
  https://www.disabilitystatistics.org/
- Department of Labor disability employment statistics
  https://www.dol.gov/odep/topics/DisabilityEmploymentStatistics.htm

VCU

Notes:

Click on the links provided here to review additional resources for learning.